A Partnership Between Medical Educators, Patients, and Families

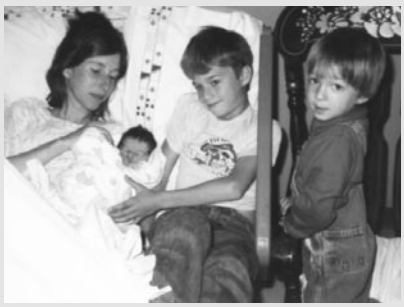
To open a discussion about partnership between medical educators, patients, and families, it might be helpful to review the idea of partnership in general and to review the way partnerships with patients have been conceptualized in health care. According to Webster's dictionary, a partner is "a person who takes part in some activity in common with another or others."[1] In a partnership, each party makes a substantial contribution to the effort, task, or enterprise. An approach that involves patients and families as partners in medical education sees them as important to the whole process of medical education, from identifying curriculum content to defining competencies for medical education, and from designing educational activities to co-teaching and addressing evaluation.

"The purpose is to try to help the students understand what it's like to be a patient, so that they will have more empathy for the patient and they'll be able to express that concern so the patient doesn't feel abandoned."

–Florence Rollwagen, Ph.D.
patient-advisor

Learning about Relationships and Health Care

Healthcare planners, healthcare providers, patients, and families have been re-thinking relationships in health care for quite some time. Many authors have focused the conversation about relationships between patients, families, and healthcare providers on the model of partnership, with joint planning, shared decision making, and active participation of patients and families with physicians and other healthcare providers. These authors emphasize the importance of learning to identify common goals and to respect and value differences of perspective.[2] Extending this idea to medical education helps build curricula that incorporate the perspectives of the various partners in health care and equip medical students to enter into collaboration with their patients as they begin to practice medicine. Medical students learn about physician-patient relationships from the very beginning of their medical education as they listen to patients' views and learn from them.



"It's a great opportunity to potentially make a difference, to educate students. There is a lot to say, many parents to learn from. Having the opportunity to hear the parent/patient perspective is so important."

–parent-advisor

What do Patients and Families Bring to Medical Education?

Patients and families bring a unique contribution to medical education. They can provide:

1. ***Descriptions*** of the complexities of living with chronic medical conditions and examples of ways doctors can be helpful.
2. ***New ideas*** for medical education.
3. ***Reminders*** about the difference doctors can make in people's lives.
4. Stories that build ***empathy and appreciation*** for people.
5. ***Opportunities to practice collaboration*** between patients and students or patients and physicians.

1. Descriptions and examples

Most people with significant illness go to the doctor, spend time as patients in hospitals, fill prescriptions, and live life while following physicians' recommendations. They live with illness, get better, practice preventive health care, and manage their medical conditions. They can recount innumerable examples of experiences with physicians that can bring constructive ideas to medical education. These examples can help students and residents talk with patients and families, formulate practical recommendations, and learn what patients and families need and want from their doctors. Furthermore, people who have experienced many medical encounters can provide detailed behavioral descriptors of physician attributes and abilities that meet the needs of patients and families. Their descriptions are down-to-earth and practical, because they come from experience. For example, a focus group facilitator asked a small group of people with chronic medical conditions what it would mean to live life well with their medical conditions. One person replied, "That means learning to tie my shoes again." Another answered, "That means being able to cook dinner for my family." The discussion that ensued led to the development of a session to teach students how to talk with patients about the context of their lives and to jointly plan interventions that address patients' practical goals for living life every day. Another poignant example emerged from a group of parents of children with special healthcare needs. They were asked to describe the kind of

communication they want to experience with their children's physicians. The parents responded by writing a competency about communicating with children, and delineated the following skills and abilities:

- Listening.
- Communicating with children at appropriate developmental levels.
- Acknowledging each child as a person.
- Developing a relationship with each child.
- Observing non-verbal communication.
- Talking to children in a way that will make them comfortable.
- Talking to children about their medical conditions.
- Giving children control over their situations.
- Making eye contact with children.
- Putting children at ease with play.
- Asking questions based on what a child has said.
- Matching language to age, culture, and educational levels of children.

This list of abilities informed the planning of an hour-long session on conducting a pediatric interview.

"What a great idea, to have students talk to patients, and find out what they want from the relationship with their doctors."

–Mark Haigney, M.D.,
medical educator

"[F]amilies are visionaries. Their dreams are not tied to bureaucratic limitations. Their ideas and hopes for their children, their families, and their communities provide challenge, inspiration, and guidance."

–Elizabeth S. Jeppson and
Josie Thomas, 1995,
Essential Allies: Families as Advisors

2. New ideas

Patients and families bring a new perspective and fresh ideas to medical education. When writing competencies for medical students or residents, they emphasize different behaviors than a medical educator might. When planning educational activities, they think of alternative approaches and highlight new learning objectives. Home visits started in the Pediatric Clerkship at the Uniformed Services University because a parent said, "Please send the students to my house, so I can show them what life is like with my son." The families helped plan an approach to home visits that directs students' attention to families' resilience and how they negotiate daily challenges of medication schedules and therapy appointments around carpool commitments and soccer practice. Similarly, the Family Medicine Clerkship shifted the focus in

their home visit from an analysis of a patient's medical condition to an opportunity to learn about the resources that patients and families need when they live with chronic health conditions or disabilities. In these Family Medicine home visits, patients and families describe their needs and capabilities and teach students about resources that help them live their lives.

"This might help prevent people forgetting why they went into medicine."
–Mark Haigney, M.D.,
medical educator

A group of parents or patients with a skilled facilitator can translate concrete examples of physicians' behaviors into implications for medical education. When a medical educator invites suggestions for the educational program, creative ideas emerge in the discussion. The group starts with isolated ideas that become insights and converge as co-created educational plans. One idea leads to another, and something emerges that neither a group of educators nor one patient or family member would think of alone. As the group begins to critique the ideas, an educational plan emerges that is worth a try.

3. Reminders

Most students enter medical school hoping to learn how to help people, and most of them graduate and enter residency hoping to become the kind of physician who makes a difference for people. Sometimes they lose sight of this goal in the midst of volumes of information and hectic schedules. Listening and talking with people who share insights and gratitude about their doctors reminds students and residents how doctors can affect the lives of patients in a positive way. The energy and passion of patients and families also invigorates medical educators. The enthusiasm of patients is infectious, and their stories help educators, students, and residents remember what is important about touching the lives of one person at a time.

"I went into it a little skeptically … But then about a half hour into it I realized, wow, look at this. I've got patients really telling me what they feel, whereas I don't know if I would ever get that opportunity again."
–Jeffrey Lackey, medical student

4. Empathy and appreciation for people

As they master anatomy and pathology, it is important for students to remember that organ systems reside in people's bodies and diseases happen in the context of people's lives. When patients and families participate in medical education, students and young doctors understand that patients and their families are people with lives beyond their diagnoses. Conversation about treating patients as whole people begins to make more sense. Students acquire perspective and depth to their empathy and compassion as they hear about patients' experiences. They also of-

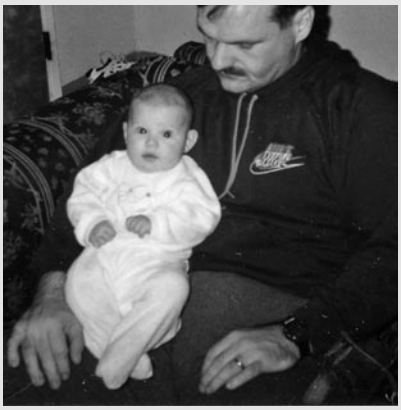
ten begin to realize that patients' experiences could happen to them, or to their father or child or sister.

5. Opportunities to practice collaboration

Involving patients and families in medical education also brings an experience of partnering to medical students or residents in the educational setting. Patient and family advisors bring a willingness and ability to become coaches to students, providing targeted, straight-forward, and practical feedback and becoming partners in learning, answering honest and probing questions. When they experience partnership in an educational setting, students and residents begin to see the advantages of partnering with patients and families in health care. As students develop thoughts and attitudes about what patients and families bring to interactions with physicians, they hear the views of real patients and families in the background, and these views from people's lives influence the students' developing attitudes. For example, one parent offered the following perspective on people who search the internet for information about their own illnesses or medical conditions in their families:

> "Patients and families provide an unparalleled resource to the care providers. A motivated patient can assist in providing pertinent personal information necessary to treatment. They can research information on therapies, scour recent journal articles for new and innovative approaches, or use the internet to network with individuals sharing their diagnosis. The patient or family can then bring this information with them to their visit for the physician's opinion."
>
> *-Kathy Vestermark, parent- and patient-advisor*

Students or doctors thinking about patients searching the internet for medical information may not arrive at this view that parents can bring helpful information from the internet into the healthcare setting. Particularly junior members of healthcare professions may worry that the patient's searching indicates a lack of confidence in healthcare providers. Hearing a positive perspective early in their careers might help them enter their own relationships with patients prepared to look at their patients' research as a strength and ready to approach their patients as true partners in health care.



"We can give a different view. We don't have anything but hope, encouragement for students."

–parent- and patient-advisor

"We possess a unique piece that we can help students understand – the struggle that parents face with a child with special needs. Life might have to go in a different direction than you hoped."

–Charles Engel, parent-advisor and Human Behavior Course Director

Why are Medically-Experienced People Well-Suited to this Role?

Not everyone who goes to the doctor thinks in detail about the doctor's way of interacting, conveying information, or making decisions with patients. However, people who have had intense or frequent medical experiences often attend to the details of healthcare encounters, because these encounters affect their lives on a regular basis. They tend to notice what physician behaviors and attitudes facilitate good communication, help them make decisions, or lead to recommendations that assist in dealing with the challenges of their medical circumstances. As a consequence, many people living with chronic conditions become sophisticated in their ability to describe and critique health care. There is much to be learned from such patients and their family members. Involving many people who have had many different experiences helps students learn to interact with people from many different backgrounds.

Furthermore, intense medical needs require and create a different relationship between patients and physicians or parents and physicians. Understanding this evolution helps prepare medical students and residents for these relationships, which may demand more energy and skill of them as physicians. As one parent said,

> "If you bring in your child for a routine physical, if the physician is a little gruff, it's no big deal. If your child has a serious special healthcare need, you're hanging on every word, and are more vulnerable to the impact of gruffness, lack of information shared, etc. If there's no big deal, the little things may go unnoticed.… If there's a big deal, all the little things matter and their meaning is magnified, their absence is more noticeable. People with heightened awarenesses are more attuned to what needs teaching."

What Facilitates Successful Collaboration?

As we have learned how to involve patients and families at the Uniformed Services University, we have spent some time reflecting on the attitudes and ways of interacting that build successful partnerships. Partnerships flourish when medical educators make a conscious effort to do the following:

1. ***Think about what partnership means.***
2. ***Value different perspectives.***
3. ***Look for strengths*** in patients and families.
4. ***Intentionally facilitate*** an environment that invites ideas from patients and families.
5. ***Listen closely*** to patients and families.

"Partnering sets the stage for an atmosphere of mutual respect."
–Kathy Vestermark, parent- and patient-advisor

1. Think about what partnership means

In some ways, patients have always been involved in medical education. Physicians have always observed their patients to learn about health, illness, and healing. Medical educators for decades have invited patients into classrooms so students could see medical conditions in real patients. Clinical experiences in medical school and residency have formed the cornerstone of medical education. Involving patients and families as partners in medical education, however, goes beyond this. It means moving from bringing patients in as exhibits or objects of study to involving them as full collaborators. It means creating ways to involve patients and families as co-planners, co-creators, and co-teachers. It means figuring out what patient-centered, family-centered, and relationship-centered care mean in medical education, so that medical students and new physicians gain the experience needed to comfortably practice medicine in relationship-centered ways.

"One teaching experience with students ended with my explanation of good medicine as one-half medicine, one-quarter common sense and one-quarter compassion. A student came to me afterwards and said he had never thought of medicine beyond traditional treatment."
–Carolyn Jordan-Alexander, parent- and patient-advisor

2. Value a variety of perspectives

As knowledge becomes more complex and expertise more technical, academics and researchers tend to become more specialized. Physicians, medical researchers, and medical educators are no exception. Still, there is something to be learned by cultivating a cross-disciplinary perspective—by looking everywhere to learn what one needs to know, by consulting with people who have a perspective different from one's own,

"I think I taught a lot of young, to-be doctors about the importance of interacting with parents, the importance of understanding many perspectives, and the viewpoints of families."

–a parent-advisor

and by looking for insight and understanding in unexpected places.[4]

The viewpoint of the patient will always be somewhat different from that of a physician. Medical students and physicians can expand their perspective when they realize that in their roles as physicians, they sometimes cannot see the parent or patient's view. What is obvious to physicians is not always obvious to patients, and vice versa. There are questions about life as a patient that a physician cannot answer alone, even if that physician has had his or her own patient experience. Physicians do not entirely lose their professional perspectives, even when they are sick. Even if they did, their experience would be the experience of just one patient or just one family member. Other patients and family members will see health care differently given their own backgrounds, cultures, languages, experiences, and needs.

3. Look for strengths in patients and families

Initially, a group of patients and families who gather to talk about healthcare experiences may discuss their negative or painful experiences. Not all patients and family members will immediately know how to focus their observations to articulate succinct educational objectives and plans. However, when medical educators focus on potential contributions and look for strengths in the stories shared by patients and families, they will find many. When educators learn to listen for innovative ideas and creative thoughts, they will hear them. When they learn to ask questions that elicit a wide range of patients' perspectives and convey an expectation of useful insights, the resulting discussion will be useful and informative.

A focus on strengths and helpful ideas from patients and families also leads physicians and medical educators to another fundamental shift in attitude. One observer has reflected a shift in the thinking of physicians toward more appreciation for the strengths of patients and families in this comment:

> "It used to be that professionals held all the capacity and patients were seen as passive, helpless, and dependent. No more; the new professional role is closer to that of coach, helping patients be as capable as they can, and stepping in only when their needs exceed their capacity."
>
> *-Anthony Suchman, M.D., physician, medical educator, and researcher*

When medical educators bring together a group of medically-experienced people, the gathering is not a support group. Patients and families do not gather in this context as needy people, but as contributors to the medical education process.

"It's always valuable to share your story, your journey. It's an emotional experience."

–a parent-advisor

4. Intentionally facilitate an environment that invites patient ideas

Some information and ideas will be gained by gathering a group of patients and families and simply listening to what they have to say about doctors. Many of their stories will find a place as examples in medical education, and many patients and families will talk about what doctors do that helps or hinders them. Much more is to be gained through intentional facilitation of discussion and planning for a particular topic in a medical curriculum. An effective facilitator can focus the group's discussion, put forth targeted questions, guide the group to develop a product, and create an environment that is productive and constructive. When this happens, patients and families can enter the discussion with enthusiasm and contribute their expertise.

5. Listen

Working with patient and family advisors in medical education is fundamentally about listening. Building a successful partnership between educators and advisors with experience as patients and families requires setting aside established curricula and prior experience to listen to new perspectives. When medical educators take the time to listen carefully to patients and families and develop curriculum activities that teach new physicians how to meet the needs that patients and families describe, partnership emerges. The partnership between educators and these experienced advisors assures that curricular activities will teach medical students material relevant to challenges for today's families.

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